

SINGAPORE EPILEPSY FOUNDATION *Newsletter*



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Editorial

Dear reader and Singapore Epilepsy Fellowship member, the year is fast drawing to its end, but before we conclude the year, we would like to present you this year's last newsletter.

Make the time to attend the International Epilepsy Day on the 7th December 2003. Time: 11.00 am to 21.00 pm. Please note the venue: HDB HUB Toa Payoh Center. For details please check our website: www.epilepsy.com.sg.

This will be a fun-filled meeting aimed at raising funds for those in need and suffering from Epilepsy. Hopefully this will raise awareness of the many problems facing those with epilepsy and so enable moving towards resolving these! Also find details on how the Work Skills Training Programme is a useful adjunct for improving everyday work skills. The main part of this edition recounts the personal experience of dealing with problems at and around work resulting from epilepsy.

Many suffering from epilepsy will be familiar with the problems presented here. This story not only tells you about the problems a diagnosis of epilepsy may generate but also gives important personal advice on how to deal with these.

The Editor

Activities and News

TV Interview with Epilepsy



As part of the awareness campaign, an interview about epilepsy was featured in Klinik Kita (a malay program by Suria Channel). The program which will be telecast on 27th November, Thursday, is hope to educate the public about knowledge of epilepsy and problems faced by people affected with epilepsy.

(L-R) Ms Mariah Rosman Ismail, Mr Aarron Aziz, Mrs Lina & Ms Jamilah

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Epilepsy Care Coordinator

Siti Jamilah Senin



My Job Experience

Good afternoon everyone, it is indeed an honour to be here before all of you today. I would like to thank Dr. Lim Shih Hui for inviting me to share with you my working experience over the past 1 year.

Before I begin on my working experience, allow me to share with you a little about my past. I started to suffer from epilepsy when I was about 12 years of age. However, I did well enough in my education to qualify for university. Before I commenced on my university education, I even worked part-time as a relief teacher for 5 months. I truly hope this short introduction about myself can be a source of encouragement for everyone in this support group. Just like all of you here, I believe that epilepsy should not be a death sentence because every human is special and talented in his or her own ways.

Being meaningfully employed is a goal that most people strive for, including us epilepsy patients. Of course, besides being guaranteed an income to keep us going in life, there are often many other rewards that are as important such as satisfaction for a job done well and the knowledge that others have benefited from our efforts.

I remember that when I sent in my resume to apply for the job of a probation officer, I thought to myself, "Should I declare that I have epilepsy?" Just like all of you, I knew that if I were to declare, my medical condition would block the path ahead of me. My qualifications would mean

nothing, peanuts maybe. My medical condition would be like a bright light glaring into the eyes of my employer and he wouldn't even be able to see how well I have done in my studies. In addition, I remember that I was attending some support group meeting about 2 years ago and this lady was saying that when she declares her medical condition right from the start, her job application would be rejected immediately. And even when she declared after being on the job for some time, they would still ask her to leave and she was kicked around like a ball from company to company, job to job.

We know that workers with epilepsy can face obstacles: negative and uninformed attitudes, outright discrimination, under-utilization of our skills...the list goes on. As a result of the above, I chose not to declare that I have epilepsy. I knew that in a way, what I was doing was wrong but I refused to be discriminated and I did not want to run the risk of my employer focusing on my medical condition rather than my ability to do a job well.

I must say that words cannot describe the happiness I felt when I was offered the job as a probation officer. This has been my ambition since my university days. My job often requires me to work overtime, running from household to household, typing reports until late at night, coming up with programmes to better serve my clients but I do not mind. After all, my parents and loved ones have been such a great support to me that I feel it is only right I contribute back



The author graduated from local university.

to society in my own ways. In fact, I always tell my friends I love my job so much that it is more a hobby than a job. I don't find that I am dragging myself to work each day. In fact, each day I wake up feeling happy and I know that I am really blessed to have found a job I love. It is really a joy to be able to help others, to be able to provide advice and counselling to people. What makes me really happy is to see my clients' problems solved.

But what about my, or perhaps I should say, our problems? My sky didn't remain blue. I had a seizure a few months after I started work in the presence of my colleagues. Perhaps for me, things are a little simpler because my epilepsy was diagnosed as that of complex partial seizures, or in simple terms, a mild version of epilepsy. That is, I become disorientated for a minute or so. My colleagues didn't question me initially but a few months later, sometime this year, my immediate supervisor suggested I should inform my Assistant Director about my condition. At that point, I really didn't know what to do. I needed a listening ear so badly that I even thought to myself, "Can I switch positions and be a client while my clients be my counsellor?" I was really at a loss because at that time, my condition was improving. I was free from seizures for 3 months, which is to me and my loved ones, a miracle considering that I get my seizures a few times a month. Even up till

today, I wonder what caused this miracle. If I may use my doctor's words, it could be a cocktail, that is, a mixture of factors. What do I mean by that? My father thinks it is the change in medication I had, my mother thinks it is the essence of chicken I have been taking daily while I think it is the healing service I have been attending every Saturday at a Church Lighthouse Evangelism because wonderful miracles have taken place there.

After some serious consideration and discussion with my parents, I decided to go ahead and declare that I am suffering from epilepsy. And oh goodness me, when I did so, the sky turned grey immediately. I would never forget that day. My Assistant Director was really unhappy and angry with me when she heard the news. She asked me straight in the face, "Why didn't you declare your medical condition right from the start?" And I replied, "I wanted to be given the opportunity to prove myself first, to prove that I can do my job as well as all the others here who are healthy." But what I said didn't seem to help. I was lost...close to tears. Fortunately, I had the support of my parents and my boyfriend who were by my side all the way, encouraging me and telling me to take things easy. The love and concern from them made things more bearable and I would like to take the opportunity today to thank them for all that they have been through with me. Frankly, I wouldn't have made it without their support.

A few hours later, I picked up the courage, knocked on my Assistant Director's door again, sat down and told her, "I understand why you are angry with me and I know I was wrong not to declare my medical condition right from the start. But I hope you understand that this is a job I love and really wanted." I suppose by that time, my Assistant Director had thought things over and understood how I felt. She brought me to my Deputy Director and she decided that my performance has not only been stable but it has

been good and as a result, they decided to allow me to continue working there. With the support from my Assistant Director, Deputy Director and Director, I made it through this rough patch. I must really say a big thank you to them, even though they may not be present, for not kicking me around like a ball, from company to company, job to job. Of course, I must say a big thank to my doctor who has also been supportive. His medical report affirmed the Human Resource department that my epilepsy is well controlled and would not affect my job as a probation officer. In a way, his letter was like a shield for me and after a few days, the Human Resource department decided that I could continue with my job.

I must say those few days must have been the most stressful days in my working life. The anxiety I felt is indescribable. Dark clouds hung over me and my tears often rolled freely. However, I must say I really thank God for the opportunity to continue with my job and to help provide for my family because I know my parents have been through a lot for my sake.

What is most interesting here is that after I declared my medical condition and everything was settled, my Assistant Director and Deputy Director didn't look at me in a different light. In fact, they are still supportive and are treating me the way everyone else is being treated. They have helped me to see that not every employer is unconcerned and that there is still compassion in them. I suppose this is what people mean when they say, "Behind every dark cloud is a silver lining."

In fact, I just received my job confirmation from my Human Resource department yesterday. However, I am employed under the terms of clause A95, which means that I am not eligible for paid sick leave if I am ill directly because of epilepsy. What was really heartwarming was that my Director and Deputy

Director even sent their warmest regards and congratulated me.

However, even up till today, I believe I wouldn't have declared my medical condition even if I knew this would happen. Of course, there are pros and cons involved. To me, if I had declared my medical condition right from the start, I would probably have a peace of mind and not suffer so much. But at the same time, I would probably be running the risk of disqualification or discrimination. I chose to declare my medical condition later because it gave me the opportunity to prove myself on the job prior to disclosure.

I do not know which is the best option. I am no expert here but what I truly believe is that if you think an employer needs to know that you have epilepsy, then it is better to tell them rather than to have them find out for themselves. I am sure none of us wants to get into trouble. However, I also understand that different people have differing opinions so the final decision really lies with you as an individual. Like I mentioned earlier on, every person is special in his or her own ways. I want to make use of this opportunity to encourage all of you not to give up but to persevere on. **"Life is already too short. We can choose to make every moment count or to curse the darkness around us. Surely there would be disappointments. Things do not always turn out the way we want them to. But eventually, hope returns."** I am sure all of you have heard of the saying, "When the going gets tough, the tough gets going." It is great to see how supportive family members and loved ones who are seated in front of me can be. Love and support from family members and loved ones are sometimes what keeps up epilepsy patients going in life and I strongly believe all of you can and will make it in life. I would like to say I am really happy with the way my life is now and it is my sincere hope that everyone would be as happy, if not happier than I am.

Lastly, I would like to dedicate a poem to 2 very special people in my life, my father and mother, for all that they have done for me and their support for my job and the stress I sometimes have to undergo:

How blessed I must be,

To have loving parents surrounding me;

When I need a listening ear,

I know I need not fear;

For I have loving parents by my side,

Who would willingly be my guide;

For all the help during patches so rough,

I would never be able to thank you enough.

Christina

Work Skills Training Programme *(WSTP)*

Singapore Epilepsy Foundation in collaboration with Crison Consulting is organizing the Work Skills Training Program (WSTP). This program is designed for people with epilepsy who are economically active but yet unemployed. WSTP provides the essential skills in planning your career, searching for jobs, dealing positively with job losses and economic changes. The program helps you to understand changing labour market and manage the challenges in relation with job finding.

The full day programme lasts 4 days. Classes are conducted during weekdays from 9.00 am to 5.00 pm. Each class is limited to 15 participants. There are a total of 3 modules under WSTP. Currently we are commencing the 2nd intake.

Module 1: Managing Emotions; Financial Impact & Planning (1 day)

Help you to cope with changes in your job or job loss. You'll be taught how to build strong emotional support from friends and family and enables you to identify the stress aggravating factors. You'll also learn about financial planning and public assistance available.

Module 2; Managing Expectations; Self-Assessment & Planning (1 day)

Discover your strengths and re-assess your career goals. Learn about the current employment market



and opportunities. You'll also be taught how to identify jobs that are right for you and manage career changes effectively.

Modules 3: Writing & Interviewing Skills (2 days)

It gives you practical knowledge in job search and application. Learn job hunting techniques and job application skills like writing effective resumes and role-play on interviewing.

We encourage more people to sign up for this free program and apply what's been taught as a source of reference to secure employment. So far 17 participants had benefited from this program. During the course, you will make new friends and have the opportunities to share your experiences with each other.



Activities and News



(L-R) Ms Jamilah (Care Coordinator), Dr Lim Shih Hui (Council Member), Prof Lee Fook Hong (Chairman of Singapore Epilepsy Foundation), Mr Michael Hills (1st Vice President of IBE), Ms Tak Fung Hong Anchor (President of Hong Kong Epilepsy Foundation), Mr Phillip Lee (President of IBE) & Prof Marshal-Mo Song Hsi (Chair, Asia/Oceania Regional Committee)

International Epilepsy Congress

The 25th International Epilepsy Congress was held on 12th – 16th October 2003 at Lisbon, Portugal. Singapore Epilepsy Foundation who is a chapter of International Bureau of Epilepsy was among various chapters & friends from all over the world who attended the congress.

One of the topics discussed was to have global campaign to fight for insurance rights for people with epilepsy. Representatives voiced that employment is a major issue that need to be address and also suggested sheltered workshop for people with epilepsy.

(L-R) Ms Jamilah (Care Coordinator), Dr Lim Shih Hui (Council



International Epilepsy Day

Singapore Epilepsy Foundation invites everyone to the International Epilepsy Day. The whole day event is fun whelming with games, quizzes, entertaining performances and lots of lucky draws to win.

This event is aim to promote public awareness and understanding towards people with epilepsy. Come and support us at our fundraising booths. See you there!

Date: 7th December 2003

Venue: HDB HUB Toa Payoh Center

Time: 11.00 am to 21.00 pm

More details are available on: www.epilepsy.com.sg

Schedule Details

11.00 am – 13.00 pm	Viewing of exhibition area
13.00 pm – 13.20 pm	Introduction by SEF
13.30 pm – 13.50 pm	Epilepsy Quizzes – UCB Pte Ltd
	Lucky Draw
14.00 pm – 14.20 pm	Welcome Speech by Professor Lee Fook Hong (Chairman of SEF)
14.20 pm - 14.30 pm	Welcome Speech by Guest Of Honour
14.30 pm – 14.50 pm	Line Dance
15.00 pm – 15.15 pm	Lucky Draw
15.20 pm – 15.40 pm	Song – Ms Maria Rosman
15.45 pm – 16.00 pm	Games - Novartis
16.00 pm – 16.20 pm	Lucky Draw
16.20 pm – 16.30 pm	Hari Raya Song - Ms Maria Rosman
16.30 pm – 16.50 pm	Song by Mediacorp Artist
17.00 pm – 17.20 pm	Healing Room
17.30 pm – 17.50 pm	First Aid Seizure - Demonstration
18.00 pm – 18.20 pm	Silat – Perguruan Gerak Bayangan
18.25 pm – 18.50 pm	Lucky Draw
19.00 pm – 19.30 pm	Children Dance Theatre
Booths: Healing Room	SEF – Fundraising items on sale
Carriages	Art of Sliver Creation – Demonstration on silver arts
Henna Painting	